



**Down's Syndrome
Association**

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Health Series



Depression in people with Down's syndrome



The
Down Syndrome
Medical Interest
Group

A Down's Syndrome Association publication

Our resources and Information Team are here to help

Please see our website for up-to-date information: www.downs-syndrome.org.uk

If you would like to talk about the activities or where to start, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on info@downs-syndrome.org.uk.

Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300

"Mental ill health is a change in a person's feelings, thinking, behaviour and physical wellbeing that is serious enough to cause the person suffering, to impact on their relationships with others, and to prevent the person from leading their normal life." - Doctor Jenny Torr (Director of Mental Health at the Centre for Developmental Disability Health, Victoria)

Over the years we have seen an increase in enquiries from parents and carers about the mental health of people with Down's syndrome. Depression is the most common of the mood changes reported, especially for late teenagers and younger adults.

Society in general is becoming increasingly aware of the occurrence and impact of mental illness and its treatment. So too are the families of people with Down's syndrome who will no longer tolerate the 'that's just Down's syndrome, what do you expect' approach and family-carers are actively seeking to improve mental wellbeing by securing the diagnosis, treatment and programmes of support which are routinely available to the wider population. However, despite research showing that people with a learning disability in general are up to 2.5 times more likely to have a mental health condition during their lives, only around 1 in 10 is receiving treatment for it.

What are the symptoms of depression?

Depression is at least as common in people with Down's syndrome as it is in the general population and affects them in the same way. It is much more than just feeling sad or low for a while. There is a wide range of symptoms, some more common than others, which persist for at least two weeks and often considerably longer. The depression may have appeared relatively quickly or may have developed gradually over many months, and is characterised by the changes in the table below.

Very common	Common
Feeling sad or unhappy, crying, sobbing	Weight loss
Not smiling or laughing	Decreased appetite
Moody, irritable, grumpy, angry	Loss of confidence and self-esteem – I can't do that, no-one likes me
Restless, cannot relax	Guilty feelings – I'm bad, it's my fault
Loss of energy, fatigue, slowing down	Mood at worst in mornings, improving during the day
Not enjoying favourite activities, avoiding usual activities	Self-injury
Problems falling asleep, waking often, getting up early	Damaging property
Apathy	Constipation
Withdrawal from family and friends and less communication/interaction	Anxiety
Talking in whispers/not talking	Obsessions/compulsions
Avoiding eye contact	Complaints such as recurring body aches and pains, breathing difficulties, nausea, skin rashes, frequent urination and diarrhoea, with no identifiable physical cause
Self-absorbed, inattentive, unresponsive	
Less concentration, not completing tasks or activities	
Decline in self-care skills, independence and spontaneity	

Diagnosis

A standard psychological assessment will be needed to diagnose depression. This will rely on a thorough reliable history, physical examination and investigations such as blood tests and an assessment of the patient's mental health.

In the general population, self-reporting of the way the person is thinking and feeling is routine in a medical interview as part of the diagnosis process. This is not reliable for people with Down's syndrome whose learning disability affects the way they think and express themselves. Instead, it is crucial to have reliable witness reports from those closest to the person who need to observe objectively and describe changes in their behaviour and demeanour. To facilitate this, Dr Jennifer Torr, Director of Mental Health at the Centre for Developmental Disability Health Victoria (CDDHV) has developed the 'Depression in Adults with Intellectual Disability Checklist for Carers'. This has proven to be an extremely useful tool to be completed by a family member or paid carer before meeting with the person's GP.

It is available on the CDDHV website

<http://www.cddh.monashhealth.org/index.php/depression-in-adults-with-intellectual-disability-checklist/>

Factors which contribute to depression

Mental wellbeing is influenced by a complex interaction between a range of factors including brain function, physical health, social health, psychosocial response and the person's ability to communicate about the impact of these factors on them.

Brain function

The basic way the brain is working can play a significant role. Anything which disrupts the ability of brain cells to receive and process information will increase difficulties in mood, behaviour, personality and language.

Biochemicals called neurotransmitters are important in the transfer of electrical information impulses between brain cells. Depression is thought to be related to a decrease in the neurotransmitter serotonin. Research studies suggest that there may be a relative decrease in serotonin in the brains of people with Down's syndrome. The presence of epilepsy, with its disruption of nerve pathways may further increase the risk for depression.

Physical health

It is important to identify and treat any possible underlying medical problem which can contribute to mood and behaviour changes, such as ear or urinary tract infections and chronic constipation. There are also other long standing health issues with symptoms which can imitate those of depression.

An underactive thyroid (hypothyroidism) is common in adults with Down's syndrome and causes lethargy and a depressed mood. Treating the thyroid may be all that is needed to improve the associated depression. It may also be that thyroid dysfunction co-exists with

a separate depressive condition and actually makes it worse. Both conditions would then need to be treated.

Similarly, sleep apnoea with its oxygen deprivation and prolonged sleep disturbance can cause such tiredness that irritability and anger are commonly displayed.

Coeliac disease is a common digestive condition which is caused by a hypersensitivity to the protein gluten. It is even more common in people with Down's syndrome. The lining of the small intestine becomes damaged and unable to absorb nutrients properly, leading to weight loss, diarrhoea, fatigue and a general feeling of being unwell. These persistent symptoms of themselves can result in depression as can the malabsorption of vitamins and minerals. Gluten is found in wheat, barley and oats and any foods which are made with these cereals. Symptoms and sense of wellbeing can improve significantly with a gluten-free diet.

Please take a look at the health and wellbeing section of our website where you will find links to various health-related resources for people with Down's syndrome, their supporters and GPs.

Social health

As members of our society it is important for us to feel we have a true presence in our community, being valued and respected. This gives us a sense of belonging and being included. We take for granted the freedom and ability to have opinions, to express them and to make decisions for ourselves so that we are able to have control and influence our own lives on our own terms. We value the right to choose where to live, who to live with, who our friends are and how we occupy our time. This promotes our mental wellbeing as we feel empowered, have good self-esteem and a sense of fulfilment. There is information about supporting mental wellbeing at the health section of our website.

These basic human rights may be compromised or denied to people with Down's syndrome when others make presumptions about their needs, their wishes and abilities. These issues are compounded by an inability to communicate frustrations and concerns clearly and depression is a common response to feeling socially isolated, worthless and helpless.

Despite there being a legal framework in place concerning decision making post 16 years of age (Mental Capacity Act 2005, England and Wales), people with Down's syndrome may still have less control over their personal circumstances. Decisions about their lives may be imposed on them which are often influenced by budgetary and organizational limitations rather than what they need. There is information about making every day, financial, health and welfare decisions post 16 at the families and carers section of our website. You will find easy read information about making choices at the section of our website for people with Down's syndrome.

We are seeing small but growing numbers of adults leaving home, getting jobs, forming relationships and generally leading lives of their own choosing. Everyone with Down's syndrome will need some support to achieve the things they wish to in daily life. Getting additional day-to-day support, be it to leave home or to access social activities whilst living at home with family, takes planning and discussion between the person with Down's syndrome, their family and the local authority. The first step to getting additional day-to-day support for adults is to ask for a needs assessment from the local authority.

There is information about day to day support for adults and about where to live at the 'families and carers' section of our website. There is easy read information about living the life you want at the section of our website for people with Down's syndrome.

Psychosocial response

This relates to the interaction between social factors which impact on people with Down's syndrome and how they cope psychologically with them. It concerns the way in which people individually think and behave as they experience social environmental stresses and try to adapt.

Here are some examples of stresses that may lead to depression:

- a friend, supporter or relative moving away
- the loss of a loved one
- environmental stress such as a problem at college that a person finds stressful
- change in care provider

People with Down's syndrome are vulnerable to such life events as they struggle to understand what is happening to them and why it is happening. Feelings of helplessness are common. Lack of perspective can be shown in over-reaction to otherwise ordinary events or disappointments, with much more intense reactions lasting far longer than expected for most people. Some events can trigger responses which occur months or even years later, especially the death of a family member, carer or a pet.

Young adults with Down's syndrome can be affected by disappointments and frustrations when they realize that similarly maturing siblings and friends are able to exercise much more choice and freedom in their lives than they do, as they see them experience independence, jobs, relationships and activities, which they do not.

When their siblings leave home they not only miss having them in their lives every day but also miss their circle of friends and the regular social life opportunities they previously enjoyed. It is not unusual to find an unexpected reaction to brothers and sisters returning home in college holidays and being greeted by a confused scowl, avoidance and non-compliance instead of the previous friendly relationships and routines – and then they leave again.

People with Down's syndrome are individuals first and foremost; some people may find it hard to deal with serious illnesses in, and the loss of, those they are close to, whilst others will take the situation in their stride. It is important not to shield a person with Down's syndrome from these life events. Being open and honest with the person and supporting them to express their feelings, in whatever way they are able, may go some way towards preventing depression. However, some people, despite best efforts, may experience the loss of skills, increased anxiety and depressive symptoms.

Communication

Talking things through with family and friends is a common strategy for people in emotional turmoil and an important part of getting better. It helps them to get a balanced perspective on what is happening and provides the opportunity to reflect, to understand and to consider options for resolution. This process may be more difficult for

some people with Down's syndrome; it may be harder to find the right words to tell you how they feel, and understandably, this can lead to frustration.

Some people may let you know how they are feeling through changes in their behaviour, which may include increased irritation, anger and aggression. However, many people with Down's syndrome appear to passively accept their feelings of depression. This may be because people are simply overwhelmed by how they feel and protect themselves by shutting down. Speaking in whispers or not speaking at all is not uncommon. This may be seen as a protective mechanism to avoid the stresses of the struggle to speak. Visual clues and prompts such as photographs, signs, gestures and symbols can help people to express their emotions and needs.

Treatment

Detailed assessment of the person and their circumstances to identify potential causes and contributory factors is essential. A combination of approaches may then be most effective, including treatment for any underlying medical conditions, counselling, identifying stress factors and coping strategies, improving social health and antidepressant medication.

Medication can often lift the person's mood to enable them to engage more effectively in other treatments and gain more benefit. Drug treatment alone may well be futile if the life issues and stresses are not addressed. Antidepressants may take up to 4 weeks before reaching their full effect and should be taken for some months after the depression has lifted, to prevent it reappearing if the treatment is stopped too soon. Withdrawal symptoms can be prevented by a gradual reduction of the antidepressant over four to six weeks.

Counselling and psychotherapy can be successful for people with Down's syndrome as long as they are adapted to the individual's levels of communication and understanding; Those who have more severe learning and communication difficulties may not be able to be helped in this way; for them, treatment should focus on identifying and carefully adjusting the life circumstances which it is believed have led to the person becoming depressed.

Getting Help

Once changes in behaviour, mood or functioning have been noticed, and have lasted for some weeks, professional help should be sought. GPs routinely deal with emotional problems, but may not have experience or training in recognising and treating depression in people with Down's syndrome. Those who are closest to the person they care for can tell the GP about the changes they have noticed especially if they complete a record like the Depression Checklist to give to the doctor.

There should be a thorough physical health check by the GP to eliminate any medical problems that can also cause the changes before deciding they are due to depression.

It may be necessary for the GP to refer on to a psychiatrist with special training in working with people with learning disabilities.

There is information for GPs about depression and people with Down's syndrome at the health section of our website under annual health checks.

What you can do to help depressed people with Down's syndrome

Ask for help. It's not normal for someone to feel depressed just because they have Down's syndrome.

Be patient and remember that depression is an illness, and that most people get better with treatment and support.

Make sure that any prescribed anti-depressant medication is taken and that you know what the side effects of the medicine are. The person you are supporting may not be able to tell you if they are experiencing any side effects.

Help the person to try to communicate how they are feeling. Give the person plenty of time to express themselves, listen carefully and use simple language. Signs, pictures and their own drawings can help people to recognize and express how they feel.

Encourage eating and drinking properly.

Support and encourage familiar routines that the person you are supporting is comfortable with.

Encourage the person to continue with activities they previously enjoyed.

Remember that your encouragement and help may be met with resistance.

Provide simple opportunities for achievement. Focus on easy everyday activities and celebrate effort as well as any successes.

DON'T forget your own needs – it can be very wearing living with a person who has depression. Talking with other similar carers can help, as can having regular breaks.

DON'T think depression is a slur on your family or your care. It affects lots of people, with and without disability.

DON'T make major changes like moving home, starting a new job, changing activities or support worker for the depressed person, if at all possible. They are much harder to cope with at such a time and may of themselves exacerbate the depression.

Annual health checks for people with Down's syndrome (aged 14 years plus)

In the past people with learning disabilities have not had equal access to healthcare compared to the general population. This, amongst other reasons, has given rise to poorer mental and physical health and a lower life expectancy for people with learning disabilities. Free annual health checks for adults with learning disabilities, with their GP, were introduced in 2008 as a way to improve people's quality of life.

The annual health check for people with learning disabilities is a Directed Enhanced Service (DES). This is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced to improve healthcare and provide annual health

checks for adults on the local authority learning disability register. To participate in this DES, staff from the GP practice need to attend a multi-professional education session run by their local Trust. The GP practice is then paid a sum of money for every annual health check undertaken.

Who can have one?

Annual health checks have been extended to include anyone with learning disabilities aged 14 years or above. So anyone with Down's syndrome aged 14 years or over can have an annual health check.

The benefits of annual health checks

- additional support to get the right healthcare
- increased chance of detecting unmet, unrecognised and potentially treatable health conditions
- action can be taken to address these health needs.

How to get an annual health check

- The GP may get in touch with the person with Down's syndrome to offer an annual health check but this doesn't always happen.
- A person with Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

Not all GPs do annual health checks for people with learning disabilities but they should be able to provide details of other GPs in your area who offer this service.

What happens next?

- The GP practice may send out a pre-check questionnaire to be filled out before the annual health check takes place.
- The GP may arrange for the person with Down's syndrome to have a routine blood test a week or so before the annual health check.

Who attends the annual health check?

If the person with Down's syndrome (age 16 years or over) has capacity and gives their consent, a parent or supporter can attend the health check as well.

How long should an annual health check be?

Guidance from the Royal College of GPs suggests half an hour with your GP and half an hour with the Practice nurse.

What areas of health should be looked at as part of the annual health check?

We have produced a check list for GPs which contains information about what should be included as part of a comprehensive and thorough annual health check. This includes a list of checks that everyone with a learning disability should undergo as part of an

annual health check and a list of checks specific to people with Down's syndrome. You can find the health check list at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

Mental health should be examined as part of a comprehensive and thorough annual health check.

'Mental health problems affect 25-30%, mostly depression, anxiety, obsessive-compulsive tendencies, and behavioural issues. Depression is common in older adults, often triggered by bereavement or changes in their living situation. Discriminating depression from dementia can be difficult but is important, since the former is amenable to medical therapy. Symptoms more suggestive of depression include withdrawal and decreased appetite and speech.'

Source: Syndrome specific medical health check guide – Down's syndrome, Royal College of General Practitioners, 2017

What happens after the annual health check?

Your GP should tell you what they and the nurse have found during the annual health check. You should have a chance to ask any questions you have. Your GP may refer you to specialist services for further tests as appropriate. Your GP should use what they have found during your annual health check to produce a health action plan. This should set out the key actions agreed with you and (where applicable) your parent or carer during the annual health check. Your GP has to do this as part of the annual health check service.

Information about health issues for GPs

There is information at our website for GPs about some of the more common health conditions seen in people with Down's syndrome. You will find this information at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

GPs learning disability register

People with learning disabilities experience poorer health compared to the rest of the population, but some ill health is preventable. Over one million people in the UK have a learning disability but only 200,000 are on their GPs learning disability register.

We know that people with a learning disability often have difficulties accessing health services and face inequalities in the service they receive. The Government is asking parents and supporters to speak to their GP and ensure their sons/daughters or the people whom they support are registered. It is hoped that this drive will ensure better and more person centered health care for people with learning disabilities.

The Learning Disability Register is a record of people with a learning disability who are registered with each GP practice. The Register is sometimes referred to as the Quality Outcomes Framework (QOF) Register.

If you are not sure you are on the Register, you can ask the receptionist at your GP Practice to check for you.

The doctor may have made a note on the record that a person has Down's syndrome but this does not automatically mean they have been put on the Register. When you speak to the GP about being registered, the needs and support of the person in health settings can be discussed. This information can be entered on the person's Summary Care Record (SCR) so that all health professionals at the practice know about their needs and how best to support them.

If the person is over 16 years of age or older, they must give their consent (see section in this resource about the Mental Capacity Act 2005):

- for information about their support needs to be added to their SCR
- to which information can be shared and with whom

It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age. It's a good idea for children with a learning disability to join the learning disability register at an early age. This means adjustments and support can be put in place before they reach adult services.

Reasonable adjustments in health care

You may have heard of the term 'reasonable adjustments' and wondered what it meant. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

So for people with physical disabilities reasonable adjustments may include changes to the environment like ramps for the ease of wheelchair users. For people with learning disabilities 'reasonable adjustments' may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training.

If a patient with Down's syndrome is NOT on their GP's Learning Disability Register, then reasonable adjustments to care for that person cannot be

Resources

Banks, R., Curran J., & Hollins S. (2011). Ron's Feeling Blue. 2nd Ed. Books Beyond Words. Available to purchase at: www.booksbeyondwords.co.uk

Banks, R., & Hollins, S. (2011). Sonia's Feeling Sad. Books Beyond Words. Available to purchase at: www.booksbeyondwords.co.uk

Chicoine, B., & McGuire, D. (2006). Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioural Strengths and Challenges. Woodbine House. pp256-264

Chicoine, B., & McGuire, D. (2010). The Guide to Good Health For Teens & Adults with Down Syndrome. Woodbine House. pp51-64

Davies, J., Mason, R., & Rowling, E. (2006). You Are Not Alone – Caring for a son or daughter with a learning disability and emotional difficulties. Foundation For People With Learning Disabilities. Free download at: www.learningdisabilities.org.uk/publications/you-are-not-alone/

Munir, K. (2010). Mental Health Issues And Down Syndrome. National Down Syndrome Society, USA. Free download at: <https://www.ndss.org/resources/mental-health-issues-syndrome/>

Torr, J. (2008). Mental health for adults with Down syndrome. Voice Down Syndrome Victoria members journal. pp 4-7 – Free download at: www.scribd.com/doc/56240899/Mental-Health-for-Adults-with-Down-syndrome

Townsley, R., & Goodwin, J. (2003). All About Feeling Down. Foundation For People With Learning Disabilities. Free download at: <https://www.mentalhealth.org.uk/learning-disabilities/publications/all-about-feeling-down>

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The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

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